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American Breast Cancer Survivors

PRINCIPAL INVESTIGATOR: Hayley Thompson, Ph.D.

CONTRACTING ORGANIZATION: Mount Sinai School of Medicine  
New York, New York 10029-6574

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**INTRODUCTION:** Breast cancer survivors are at elevated risk for developing a new breast cancer compared to healthy women, and are at considerable risk for breast cancer recurrence. According to the American Society of Clinical Oncology, survivors should undergo careful breast cancer surveillance including annual mammography and breast self-exam. However, studies indicate that breast cancer surveillance among African American survivors, particularly mammography, is low, especially given the higher risk of survivors as a group. The promotion of breast cancer surveillance among African American survivors is an area that deserves special attention as cancers detected early are more treatable. One promising strategy is the adaptation of a peer-led intervention developed to increase screening among healthy African American women. The objectives of the current study are: 1) to evaluate the impact of a peer-led intervention on breast cancer surveillance intention and adherence among African American breast cancer survivors through a randomized controlled trial; and 2) to investigate the mediational pathways through which the peer-led intervention impacts surveillance intention and adherence. 409 participants will be recruited and randomized over the course of the study. Participants will be African American women age 20-74 years and diagnosed with Stage I, II or III breast cancer who previously participated in an ongoing parent project and are at least 3 months post-treatment. Once informed consent is obtained, participants will be contacted via telephone to complete a baseline interview assessing sociodemographic information, breast cancer surveillance intention and adherence, and attitudinal/cognitive variables. Participants will then be assigned to either the survivor surveillance intervention condition or control condition and those in the intervention condition will participate in the intervention. One month following the intervention, participants in both conditions will complete a telephone interview to assess breast cancer screening adherence and changes in attitudinal/cognitive variables from baseline to post-intervention. Fourteen months after the intervention, women in both conditions will be contacted again in order to assess surveillance intention and adherence.

**BODY:** The approved statement of work for the current study is included as Appendix A. Please note: we have not been able to proceed beyond the first five months of the statement of work because the Human Subject Protection Review has not been completed by the DoD's personnel (Maryann F. Pranulis, DNSc Human Subjects Protection Scientist, AMDEX), even though we submitted all necessary documentation in December 2003.

The first five months of the study were approved for various start-up tasks that are described below.

- A. **Hire and train research assistant and data entry clerk:** A research project coordinator and data manager were hired in the first year of the study.
- B. **Collaborate with co-investigators and consultants to review assessment strategies and tailoring of the survivor surveillance(peer-led) intervention:** We established weekly investigators meetings that include the PI, the project coordinator, and co-investigators (Drs. Bovbjerg and Valdimarsdottir and Ms. Jandorf). These meetings focus on intervention development and implementation issues, as well as assessment strategies.

During the first year of the study, we developed the peer-led intervention to increase breast cancer surveillance among African-American breast cancer survivors. This intervention is titled, "Survivors in Spirit (SIS)." This intervention is peer-led and will be implemented by two types of peer interventionist: 1) survivor speakers, or African-American breast cancer survivors who share their personal stories of breast cancer diagnosis, treatment, and follow-up care post-treatment, and 2) lay health educators, African American women who may or may not have a diagnosis of breast cancer who present didactic information about breast cancer recurrence risk, surveillance guidelines, and breast self-examination.

In order to tailor the survivor surveillance intervention, SIS, we conducted a qualitative study of 10 African American breast cancer survivors in order to identify factors that support and deter participation in post-treatment breast cancer surveillance and follow-up care. This work (approved by the IRB of Mount Sinai School of Medicine) was presented as a poster titled, "Factors Influencing Post-Treatment Breast Cancer Surveillance among African-American and African-Caribbean Breast Cancer Survivors:



A Qualitative Approach.” This poster was presented at the Second Biennial Cancer Survivorship NCI/ACS Research Conference, Cancer Survivorship: Pathways to Health After Treatment. June 2004. The abstract is included in Appendix B.

Appendix C presents the information included on a flipchart that will be used as a teaching tool as part of SIS presentations. This information was reviewed by an advisory board comprised of physicians, breast cancer survivors, patient advocates and health educators. The members of this advisory board are presented in Appendix D. Appendix E includes a list of brochures we plan to make available at SIS presentations.

- C. **Train peer interventionists:** Appendix F includes a Powerpoint presentation that is used to train SIS’ peer interventionist. To date, we have conducted two 4-hour sessions and trained 23 interventionists: 15 lay health educators and 7 survivor speakers, as well as 1 interventionist who has trained in both roles. As part of training, interventionists complete knowledge pre- and post-tests, which are presented in Appendix G. The mean pre-test score was 5.5 and the mean post-test score was 7.95, indicating a general increase in knowledge following training. Additionally, we have held 12 small-group practice sessions to review material presented in the formal training sessions and coach interventionists in terms of their style of presentation.
- D. **Pilot test and refine unstandardized measures:** Only one measure to be included in the assessment was not used in a published study: social influence on breast cancer surveillance, or one’s perception that other African American women both participate in breast cancer surveillance and support surveillance. We analyzed data collected in a separate study from 35 African American women never diagnosed with breast cancer. These women (mean age 52 years, sd=7.4; range: 40 – 65 years) responded to 5 social influence items regarding breast cancer screening. Together, these items demonstrated high internal consistency ( $\alpha=.90$ ). Therefore, these items will be adapted for inclusion in the current study of breast cancer surveillance and follow-up care.
- F. **Prepare data entry and participant tracking systems:** Our data manager has prepared these databases through Access and SPSS.

**KEY RESEARCH ACCOMPLISHMENTS:** There are two key research accomplishments emanating from this research to date. The first is the development of a culturally-targeted peer-led intervention to increase post-treatment breast cancer surveillance and follow-up care among African American breast cancer survivor. This intervention is titled, “Survivors in Spirit: Looking Ahead to Life After Breast Cancer Treatment.” The second key accomplishment is the completion of a qualitative study to identify factors influencing participation in follow-up care among African American breast cancer survivors. These data were used to tailor the SIS intervention.

**REPORTABLE OUTCOMES:** See abstract in Appendix B.

**CONCLUSIONS:** As Human Subject Protection Review has not been completed by the DoD’s personnel Maryann F. Pranulis, DNSc) Human Subjects Protection Scientist, AMDEX), no data has been collected and conclusions are not presented.

## **Appendix A. Approved Statement of Work**

### **Task 1: Study start-up (Months 1-5)**

- a. Hire and train research assistant and data entry clerk
- b. Collaborate with co-investigators and consultants to review assessment strategies and tailoring of the survivor surveillance intervention
- c. Train peer interventionists (recruited from the ongoing Witness Project of Harlem)
- d. Pilot test and refine unstandardized measures
- e. Prepare data entry and participant tracking systems

### **Task 2: Recruit participants, conduct baseline assessment interview for randomized controlled trial evaluating peer-implemented survivor surveillance intervention, and conduct intervention (Months 6-30)**

- a. Review database of parent project to identify eligible breast cancer patients
- b. Recruit 409 patients for randomized controlled trial via telephone and mail informed consent forms
- c. Administer baseline assessment interview for randomized controlled trial via telephone upon receipt of signed informed consent forms (expected total of baseline interviews=409)
- d. Randomize participants
- e. Mail incentives (\$20 money orders) for participation
- f. Develop schedule of survivor surveillance intervention presentations (expected total of presentations=14)
- g. Begin data entry and management

### **Task 3: One-month follow-up assessment interviews (Months 8-30)**

- a. Contact participants via telephone to administer one-month follow-up assessment interviews (expected total of one-month follow-up interviews=389 with 5% attrition from baseline)
- b. Mail incentives (\$20 money orders) for participation
- c. Continue data entry and management

### **Task 4: Fourteen-month follow-up assessment interviews (Months 21-45)**

- a. Contact participants via telephone to administer 14-month follow-up assessment (expected total of 14-month follow-up interviews=311 with 20% attrition from 1-month follow-up)
- b. Mail incentives (\$20 money orders) for participation
- c. Continue data entry and management

### **Task 5: Interim data analyses, report and presentations (Months 22-27)**

- a. Work with co-investigators and consultants to conduct preliminary analyses for report
- b. Present preliminary results at scientific meetings

### **Task 6: Final data analyses, report and presentations (Months 45-48)**

- a. Work with co-investigators and consultants to conduct analyses for report
- b. Present results at scientific meetings
- c. Prepare manuscripts for publication

## **Appendix B. Abstract of qualitative research to tailor intervention.**

**Factors Influencing Participation in Post-Treatment Breast Cancer Surveillance Among African-American and African-Caribbean Breast Cancer Survivors: A Qualitative Approach.** Hayley S. Thompson, PhD, Monique Littles, MA,, Sherly Jacob, BS, Ruttenberg Cancer Center, Mount Sinai School of Medicine. Crystal Coker, BS, New York University.

Women diagnosed with breast cancer are at elevated risk of developing a second primary breast cancer and their risk of breast cancer recurrence is significant. Breast cancer recurrences and second primary cancers detected early are more treatable and better controlled. Unfortunately, African-American survivors are approximately half as likely to participate in post-treatment cancer surveillance, specifically mammography, compared to White survivors, and their length of follow-up care is significantly shorter. There are no published data on factors that serve as motivators of and barriers to follow-up care in this population. The current study sought to address this gap in the literature through open-ended key informant interviews.

Participants were 10 African-American and African-Caribbean breast cancer survivors between 38 and 63 years of age (mean age= 50). Educational levels were reported as follows: less than high school=20%, high school=40%, Associate's, Bachelor's, or graduate degree=40%. All participants were recruited from cancer support groups or the volunteer staff of cancer outreach programs. Time since the end of primary treatment ranged from 1 to 6 years. Assessment focused on the American Society of Clinical Oncology (ASCO) guidelines for post-treatment cancer surveillance (annual mammography, monthly breast self-exam, regular pelvic exam, and a schedule of more frequent physical examination and patient symptom history). All participants completed interviews focusing on follow-up care received in the past year, facilitators of or barriers to follow-up care, and general attitudes about recurrence. An open coding strategy was applied to identify common themes using the Ethnograph qualitative analysis software program. Participants were also asked to respond to three closed-ended items about their follow-up care.

Almost all participants reported receiving specific recommendations about follow-up care from their physicians after primary treatment. However, none reported that they were given information completely consistent with all the ASCO guidelines. The most common recommendation was to increase the number physician visits over the course of a year and the majority of participants reported at least one physical exam in the past year. Only 2 participants reported receiving specific mammography recommendations but almost all participants reported a mammogram in the past year. Half of participants also reported surveillance not included in ASCO guidelines, such as blood tests, bone scans, CT scans, ultrasound, MRI, and x-rays. In terms of factors that influence participation in follow-up care, 8 themes emerged: (1) the desire to maintain good health (e.g., belief in early detection); (2) concerns and fears about recurrence (e.g., preservation of unaffected breast); (3) support from health care providers (e.g., personalized encouragement from physicians, coordinated health care, support from nurses and health educators); (4) familial relationships (e.g., support from relatives, relationships with one's children and grandchildren); (5) relationships with other breast cancer survivors (e.g., support from survivors, serving as a role model to other survivors); (6) lack of support from family or friends; (7) lack of information; and (8) medical care costs. In terms of general attitudes about recurrence, 3 common themes emerged: (1) low perceived recurrence risk or no knowledge about actual risk; (2) the role of spirituality and faith in addressing possible recurrence, and (3) the role of diet and nutrition in recurrence. There was a largely positive response to closed-ended questions, with 70-80% of participants reporting that they receive enough information about breast cancer recurrence, that emotional and psychological concerns are adequately addressed at their follow-up visits, and that they feel reassured by such visits.

These findings suggest that multiple factors must be addressed as part of efforts to increase post-treatment cancer surveillance and follow-up care among survivors of African descent. However, further cross-cultural research (qualitative and quantitative) is needed to clarify the extent to which these factors are group-specific.

## **Appendix C. SIS presentation flipchart content**

See separate PDF file.

## **Appendix D. Advisory board.**

Eloise Nobles, Witness Role Model, Witness Project of Harlem

Desiree Walker, Witness Role Model, Witness Project of Harlem

Helen M. Webber, Witness Role Model, Witness Project of Harlem

Marilyn Moore, Executive Director, Witness Project of Connecticut

Stephanie Billingsley, Witness Role Model, Witness Project of Harlem

Elizabeth Carde, Lay Health Advisor, Witness Project of Harlem

Susan H. Lee, MD, Breast Surgeon, New York Hospital Queens Breast Center

Dorothy Burch, RN

Alberta Morgan, Lay Health Advisor, Witness Project of Harlem

Reather McAllister, Witness Role Model, Witness Project of Harlem

Jenny Romero, MD, Oncologist, Ralph Lauren Center for Cancer Care/Prevention

Erica Wahl, MS, CGC, Genetic Counselor, Rutenberg Cancer Center, Mount Sinai School of Medicine

Lina Jandorf, Assistant Research Professor, Rutenberg Cancer Center, Mount Sinai School of Medicine

Bert Petersen, Jr., MD, Surgical Oncologist, Beth Israel Medical Center

Vannisha Taylor, Witness Role Model, Witness Project of Harlem

Deborah Bristol, Kings County Hospital

## **Appendix E. Brochures to be available at SIS presentations**

1. Survivors in Spirit Breast Health Resource Guide
1. When Cancer Recurs: Meeting the Challenge- (NCI)
2. Facing Forward Series: Life After Cancer Treatment- (NCI)
3. Your Guide to Breast Cancer Treatment- (breastcancer.org)
4. Your Guide to Breast Cancer Pathology Report- (breastcancer.org)
5. Genetic Testing for Breast Cancer Risk- (NCI)
6. Understanding Gene Testing- (NCI)
7. What You Need to Know About Ovarian Cancer- (NCI)
8. Financial Assistance for Cancer Care- (NCI)
9. Cancer Support Groups and Answers (Print Out)-(NCI)
10. Cancer and Careers: Living and Working with Cancer Workbook –(Cosmetic Executive Women Foundation)
11. Eating Hints for Cancer Patients: Before, During and After Treatment- (NCI)
12. American Cancer Society Guidelines on Nutrition and Physical Activity for Cancer Prevention (ACS)
13. Breast Self-Exam Shower Card

## **Appendix F. SIS interventionist training Powerpoint presentation**

See separate PDF file.

## Appendix G. SIS training pre- and post-tests.

**Please answer the following questions True, False, or Not sure.**

1.	Black breast cancer survivors are more likely to have a breast cancer recurrence compared to White survivors.	<input type="checkbox"/> True	<input type="checkbox"/> False	<input type="checkbox"/> Not sure
2.	Younger breast cancer survivors are more likely to have a breast cancer recurrence compared to older survivors.	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Not sure
3.	Breast cancer recurrence is more treatable and better controlled if it is found at an early stage.	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Not sure
4.	Most breast cancer recurrences are found within the first 5 years following diagnosis and treatment.	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Not sure
5.	Only about 2% of breast cancer survivors are diagnosed with breast cancer recurrence.	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Not sure
6.	Breast cancer survivors only need to have physical exams about once a year after the have completed breast cancer treatment.	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Not sure
7.	Breast cancer survivors should have regular pelvic exams and pap tests (at least once a year).	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Not sure
8.	Women who have already been diagnosed with breast cancer do not need to have yearly mammograms.	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Not sure
9.	Women diagnosed with breast cancer need to examine their own breasts every day.	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Not sure
10.	Chest pain and problems with breathing can be signs of breast cancer recurrence.	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Not sure



# ***Survivors in Spirit (SIS)***



## **Looking Ahead to Life After Breast Cancer Treatment**

**Mount Sinai School of Medicine  
Copyright 2004**

## **Good news about breast cancer survivors**

- ❖ There are over 2 million female breast cancer survivors in the U.S.
- ❖ About 160,000 of these survivors are African American or Black.

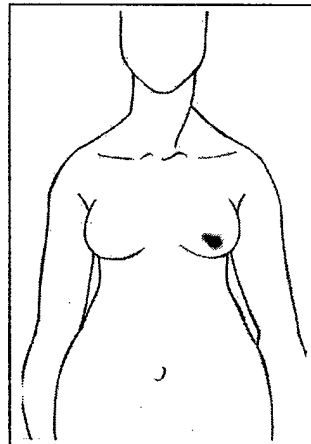


## **What is a breast cancer recurrence?**

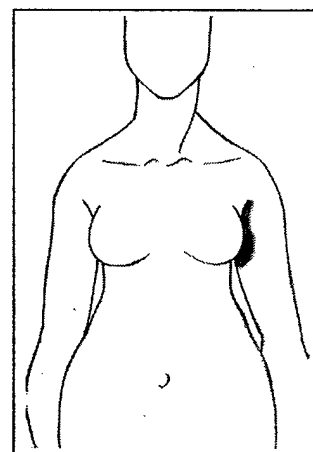
- ❖ The reappearance of a cancer that was thought to be cured or in remission, developed from cancer cells that were not destroyed by initial cancer treatment.
- ❖ Not all recurrences are the same.

# **Types of breast cancer recurrence**

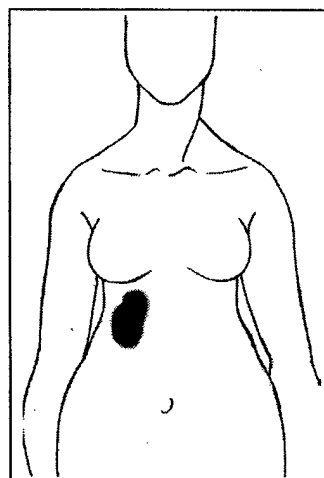
**Local recurrence**



**Regional recurrence**



**Distant recurrence**



## **How common is breast cancer recurrence?**

Survivors with recurrence at  
5-year follow-up

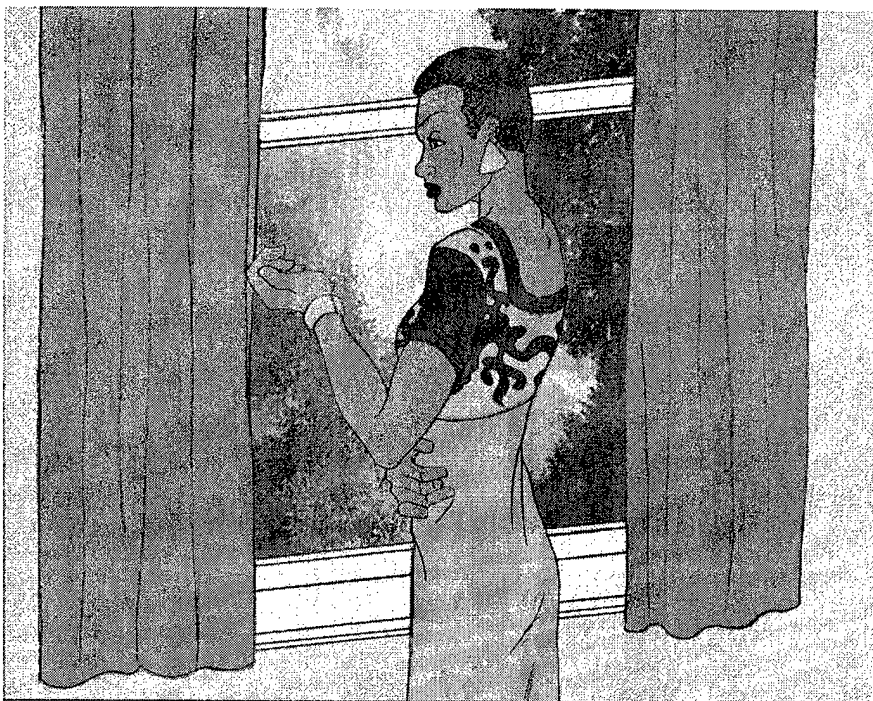
Local recurrence: 5-10%

Distant recurrence: about 20%

Approximately 70% of  
recurrences are identified within  
the first 5 years after diagnosis  
and treatment.

## Black survivors and recurrence

- ❖ Black breast cancer survivors may have less favorable recurrences.
- ❖ Black survivors do not necessarily have higher rates of recurrence.



## **Risk factors for breast cancer recurrence**

### **❖ Age**

Younger survivors are at greater risk for breast cancer

### **❖ Features of the first breast cancer tumor**

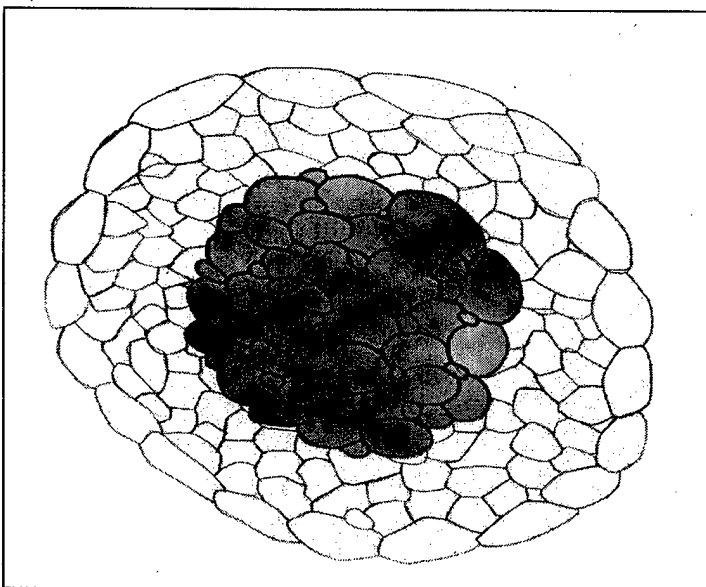
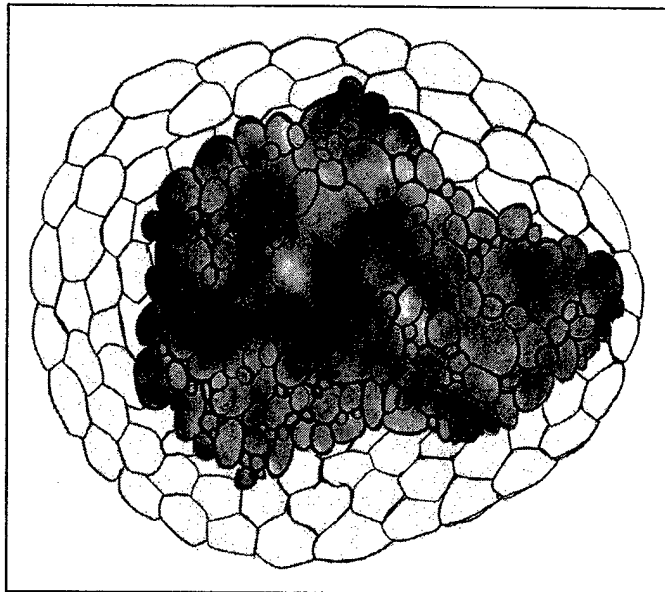
Information about one's tumor is in a pathology report that is part of one's medical records.

# **Risk factors for breast cancer recurrence**

## **Features of the tumor**

1. Positive/close and unclear or unknown resection margins:

Positive  
margins



Negative  
margins



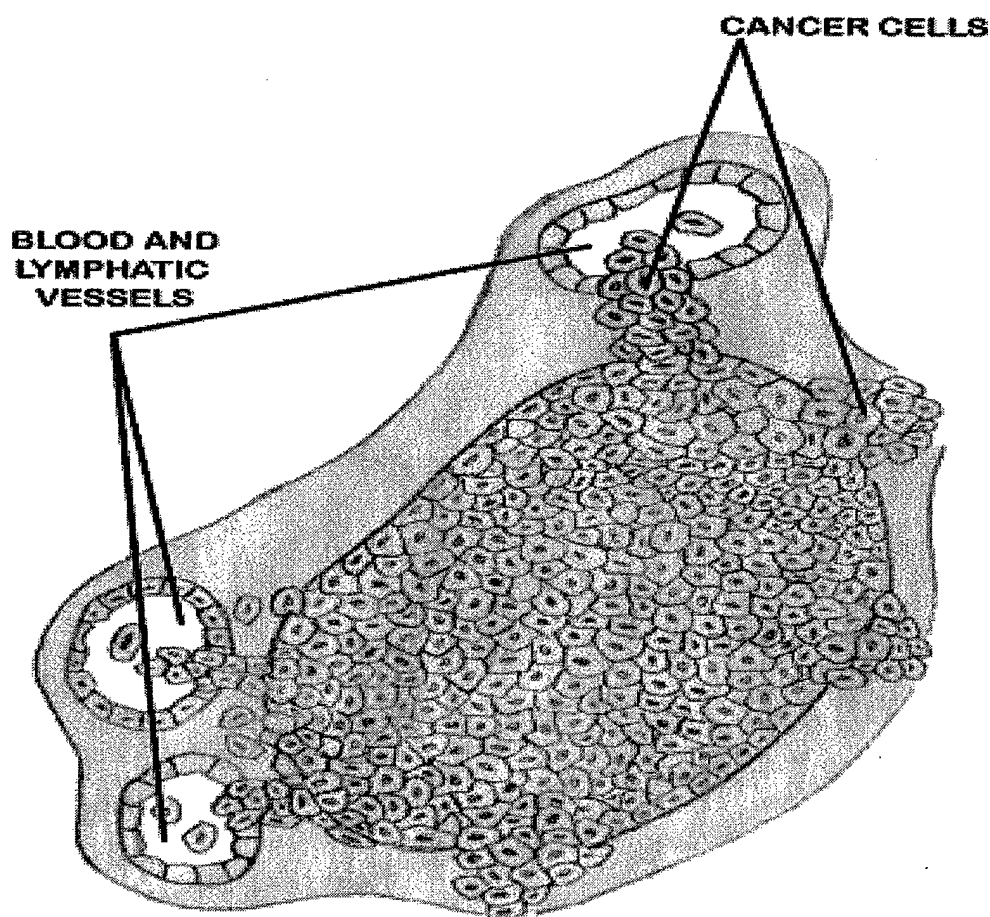
## **Risk factors for breast cancer recurrence**

### **2. Extent of intraductal cancer (cancer in breast ducts):**

The more cancer found in the ducts surrounding the tumor, the greater the risk of recurrence.

## **Risk factors for breast cancer recurrence**

### **3. Vascular invasion (cancer in blood/ lymphatic vessels)**



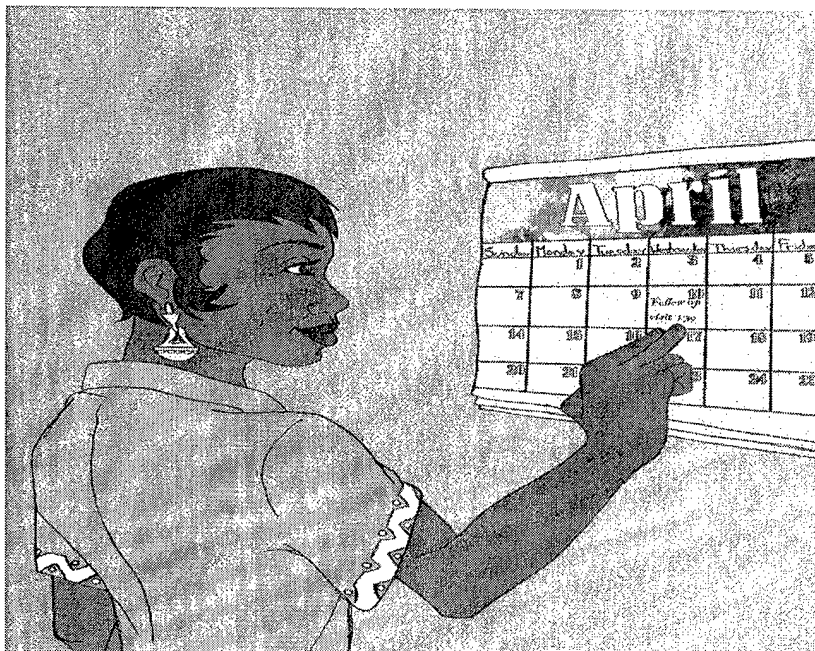
## **Risk factors for breast cancer recurrence**

### **4. Positive lymph nodes:**

The more lymph nodes that are determined to be positive (be cancerous), the greater the chance of recurrence

## Regular follow-up care and screening for breast cancer recurrence

- ❖ Regular follow-up care and screening leads to early detection.
- ❖ Getting regular follow-up care and screening can detect a tumor at an earlier stage and when it is smaller.



# **American Society of Clinical Oncologists (ASCO) Guidelines**

1. A careful physical examination and symptom
  - ✦ 2-4 times a year for the first 3 years
  - ✦ 1-2 times for the next 2 years
  - ✦ Once a year after that
2. Annual mammogram
3. Monthly breast self-exam (BSE)
4. Regular pelvic exam and pap test

## **ASCO Guidelines: Physical exam and symptom history**

- 2-4 times a year for the first 3 years (every 4-6 months)
- 1-2 times for the next 2 years (every 6-12 months)
- Once a year after that

A physical exam can detect a recurrence even if the survivor has no symptoms.

## **ASCO Guidelines: Physical exam and symptom history**

A survivor may not have any symptoms or signs of breast cancer recurrence.

However, about 70% of recurrences are detected by patients themselves based on symptoms they notice between routine visits.

## **ASCO Guidelines: Symptoms of Recurrence**

1. Any changes in the breast
2. Bone pain or tenderness
3. Chest pain or difficulty breathing.
4. Vaginal discharge or spotting
5. Abdominal pain
6. Seizures



## **ASCO Guidelines: Physical exam and symptom history**

7. Persistent headache
8. Changes in mental functioning
9. Problems with movement
10. Problems seeing or hearing
11. Discomfort, fullness or pain  
in upper right part of the body
12. Weight loss
13. Fatigue

## **ASCO Guidelines**

- ❖ Annual Mammogram
- ❖ Monthly Breast Self-Exam
- ❖ Regular Pelvic Exam & Pap Test

## **ASCO Guidelines**

- ❖ Studies have compared the ASCO guidelines to more extensive testing, such as blood tests, bone scans, CT scans, and MRIs.
- ❖ There is no difference between the ASCO guidelines and more extensive testing.

## **Second primary breast cancer**

- ❖ If a survivor is diagnosed with cancer in the breast that was not originally affected (the opposite breast), this is referred to as
  - ❖ a second primary breast cancer
  - ❖ a new primary
  - ❖ contralateral breast cancer
- ❖ This is a new cancer that is unrelated to the first and is not a recurrence.

# Breast cancer genetics

- ❖ Genes called BRCA1 and BRCA2 control breast cell growth.
- ❖ BRCA mutations occur in about 10% of breast cancer survivors and their families.



## **Breast cancer genetics**

Typically in these families:

- ❖ More than one person has been diagnosed with breast or ovarian cancer
- ❖ Family members are diagnosed at younger ages
- ❖ Family members may have been diagnosed with cancer in both breasts
- ❖ There may be men in the family diagnosed with breast cancer

## **Breast cancer genetics**

- ❖ Up to 64% of breast cancer survivors who carry a BRCA mutation develop a second primary breast cancer.
- ❖ For a survivor who has a BRCA mutation, the risk of developing ovarian cancer is up to 50%.
- ❖ A survivor's chance of developing a recurrence in the same breast is also increased.
- ❖ Genetic testing is available to learn if you have a BRCA mutation.

## **Black survivors and breast cancer genetics**

- ❖ It is unknown if BRCA mutations are more common or less common among Black people compared to other racial/ethnic groups.
- ❖ It is known that the chance of an ambiguous or unclear result following BRCA testing is higher among Black people.



**There are no formal screening guidelines for breast cancer survivors with a BRCA mutation.**

Some organizations recommend the same follow-up care and screening as other survivors plus

pelvic exam 1-2 times a year

vaginal ultrasound 1-2 times a year

annual serum screening for CA-125, a tumor marker for ovarian cancer

Survivors with a BRCA mutation may also have surgery that removes the breasts or ovaries to help prevent cancer

## **Follow-up care and screening among breast cancer survivors**

- ❖ A surprising number of breast cancer survivors do not get adequate follow-up care, regardless of race or ethnic background.
- ❖ Black survivors were half as likely to have a mammogram than White survivors in one study.
- ❖ The length of follow-up care for Black survivors was significantly shorter than that of White survivors in another study.

## **What keeps Black survivors from getting follow-up care?**

- ❖ Lack of knowledge about the recommended guidelines for follow-up care.
- ❖ Not asking one's doctor the right questions about follow-up care.
- ❖ Fear of being diagnosed with cancer again.
- ❖ Avoiding talk or thoughts about cancer because that experience is "over."
- ❖ Lack of support from family and friends.
- ❖ Costs of medical care.
- ❖ Lack of awareness of programs that can help with the costs of care.

## **What motivates Black survivors to get follow-up care?**

- ❖ Concerns about being diagnosed again
- ❖ Doctors' recommendations, support, care and concern
- ❖ Support from one's family
- ❖ Desire to survive to spend time with children and grandchildren
- ❖ Relationships with other breast cancer survivors
- ❖ Desire to live a healthy life

## **Take care of yourself!**

- ❖ Be active in managing your stress
  - ❖ Research does not yet show a consistent link between stress and breast cancer.
  - ❖ However, we know that stress can affect your immune system and help cause illness.

## **Take care of yourself!**

The American Cancer Society has diet and exercise guidelines for cancer prevention:

- ❖ Eat a variety of healthful foods, especially fruits and vegetables
- ❖ Lead a physically active lifestyle
- ❖ Maintain a healthy weight
- ❖ Limit the drinking of alcohol
- ❖ Be aware of food safety

## **Breast self-examination (BSE)**

During BSE, a woman is looking for any change in the breast

- ❖ Lumps
- ❖ Swelling
- ❖ Dimpling
- ❖ Changes in color of skin (redness or veins become visible)
- ❖ Nipple discharge
- ❖ Rashes
- ❖ Inverted nipples

# ***Survivors in Spirit***



**Looking Ahead to  
Life After Breast Cancer Treatment**





## What is *Survivors in Spirit*?

- ❖ *Survivors in Spirit (SIS)* is an educational program focusing on Black breast cancer survivors and the follow-up care that is recommended after they have completed primary treatment for breast cancer.
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## **What is *Survivors in Spirit?***

- ❖ *SIS* is part of a research study funded by the Department of Defense Breast Cancer Research Program.
  - ❖ The purpose of the study is to develop and test *SIS* as a way to increase follow-up care among Black breast cancer survivors.
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## Why was *SIS* developed?

- ❖ Breast cancer survivors are at risk for recurrence (having the cancer reappear).
  - ❖ A breast cancer survivor is 3 times as likely to develop a new breast cancer compared to a woman who has never had breast cancer.
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## Why was *SIS* developed?

- ❖ Once breast cancer treatment has ended, regular follow-up care and screening is important
  - ❖ Regular follow-up care can detect a breast cancer recurrence or a new breast cancer at an early stage.
  - ❖ Cancer found early is better treated and controlled.
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## **Why does SIS focus on Black survivors?**

- ❖ It has been reported that Black survivors
    - ❖ are half as likely to get a mammogram compared to White survivors.
    - ❖ are medically followed for a shorter period of time compared to White survivors.
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## **What are the goals of *SIS*?**

1. To increase awareness about the guidelines for follow-up care after breast cancer treatment among Black survivors.
  2. To increase participation in follow-up care among Black survivors.
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## **What are the guiding principles of *SIS*?**

- ❖ Black survivors will be more likely to participate in follow-up care
    - ❖ if they hear from other Black survivors
    - ❖ if they feel supported by other Black women
    - ❖ if they have positive attitudes about that care
-



# What are the guiding principles of *SIS*?

- ❖ Black survivors will be more likely to participate in follow-up care
  - ❖ if they are confident they can obtain that care
  - ❖ if they are presented with information that is specific to Black survivors





## **What are the guiding principles of *SIS*?**

- ❖ Black survivors will be more likely to participate in follow-up care
  - ❖ If spirituality and faith is emphasized along with the information they receive
    - ❖ Spirituality and faith is often an important part of the cultures of people of African descent
    - ❖ Black and Latina survivors use more religious coping methods compared to White survivors
-



## Who is part of *SIS*?

- ❖ Survivor speakers (breast cancer survivors) who
    - ❖ Share their stories of cancer diagnosis, treatment, follow-up care and well-being after treatment.
    - ❖ Express the role of spirituality and faith in their cancer experience
    - ❖ Serve as role models for other survivors
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## Who is part of *SIS*?

- ❖ Lay health educators who
    - ❖ Teach the facts about breast cancer recurrence
    - ❖ Inform survivors about the recommendations for follow-up care
    - ❖ Teach breast self-examination (BSE) to survivors
    - ❖ Provide information about breast health resources
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## Who is part of *SIS*?

- ❖ Staff members who
    - ❖ Train survivor speakers and lay health educators to conduct *SIS* programs
    - ❖ Coordinate *SIS* programs and identify survivors who would like to attend programs
    - ❖ Interview these survivors before and after the *SIS* program to determine the impact the program had on them
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# **The role of volunteers and staff is to:**

- ❖ **Educate**

- ❖ Awareness guides action

- ❖ **Encourage**

- ❖ Be positive

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## **The role of volunteers and staff is to:**

- ❖ Present facts, not opinions
    - ❖ You may risk the project's reputation by stating opinions instead of facts
    - ❖ If you are not sure about something, be willing to say so and seek out the best answer
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## How does *SIS* work?

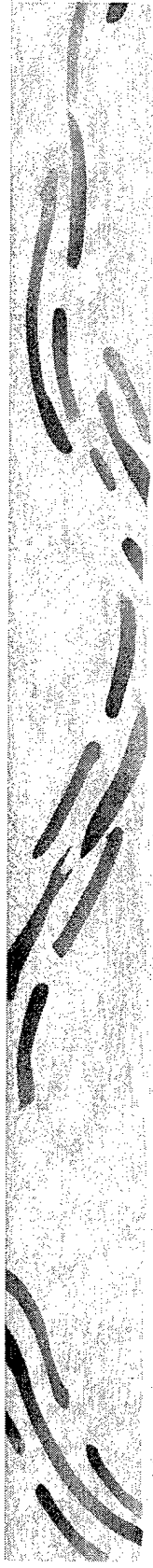
- ❖ Black survivors in the community are identified through physicians and other health care providers.
  - ❖ These survivors are contacted by *SIS* staff and asked if they are interested in being in the research study that is testing the impact of *SIS*.
  - ❖ If they are interested, these survivors are given a specific date, time, and place to attend a *SIS* program.
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## How does *SIS* work?

- ❖ Trained survivor speakers and lay health educators conduct the *SIS* program at that time and place.
  - ❖ Because *SIS* is part of a research study, each survivor speaker and lay health educator will be offered \$25 for each program she conducts.
  - ❖ We expect to conduct approximately 15 *SIS* programs over a 3-year period.
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# Good news about breast cancer survivors

- ❖ There are over 2 million female breast cancer survivors in the U.S.
- ❖ About 160,000 of these survivors are African American or Black.





## **Good news about breast cancer survivors**

- ❖ Most women diagnosed with breast cancer survive and do not die of the disease.
  - ❖ However, breast cancer survivors are at higher risk for breast cancer compared to other women never diagnosed.
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## **What is a breast cancer recurrence?**

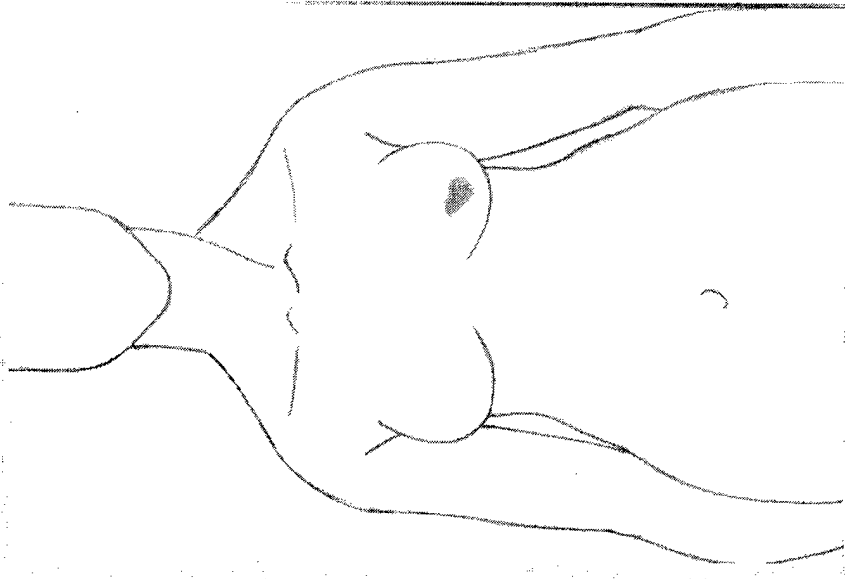
- ❖ The reappearance of a cancer that was thought to be cured or in remission, developed from cancer cells that were not destroyed by initial cancer treatment.
  - ❖ Not all recurrences are the same.
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## Types of recurrence

### ❖ **Local recurrence:**

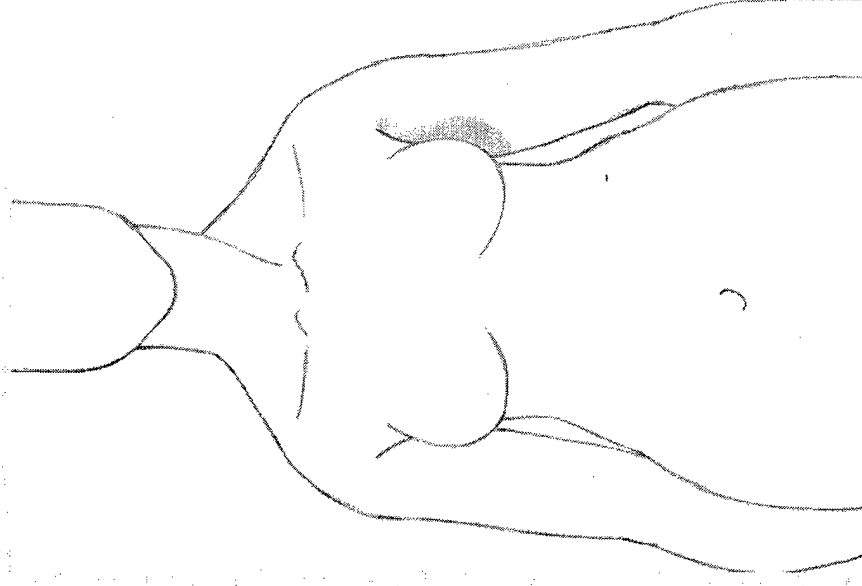
Recurrence found in the treated breast after breast-conserving treatment (such as lumpectomy) or the scar or chest wall after mastectomy



# Types of recurrence

## ❖ Regional recurrence:

- ❖ Recurrence found in nearby lymph nodes or other tissues
- ❖ May occur in axillary lymph nodes (in armpits) and/or lymph nodes in the center of the chest and elsewhere near the chest.

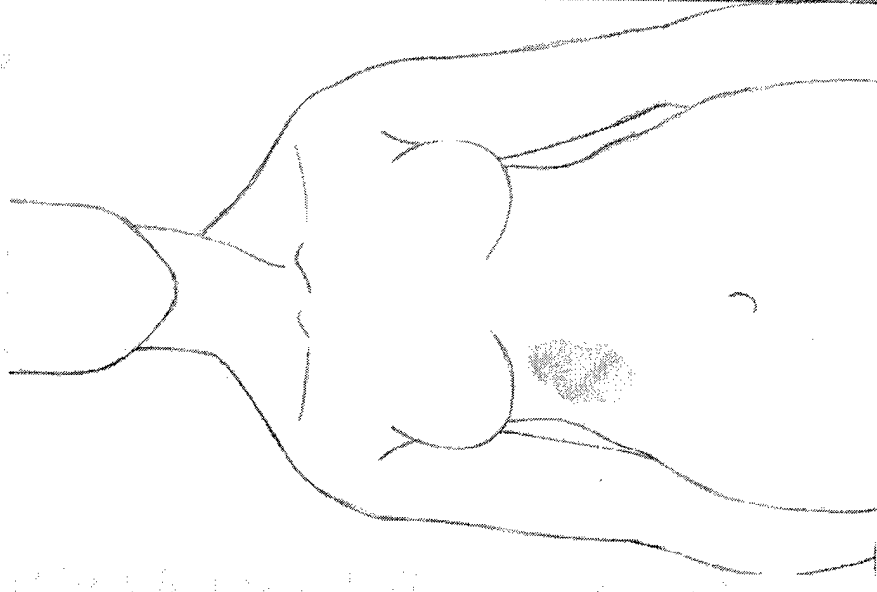


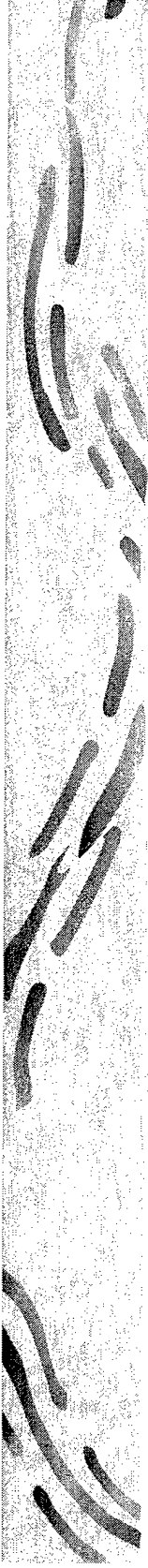


## Types of recurrence

### ❖ **Distant recurrence:**

Recurrence in which the cancer has spread (metastasized) to organs or other tissues far from the breast where it was originally found, such as liver or lungs.





## **Types of recurrence**

- ❖ Even if cancer reappears in a part of the body other than the breast, it is considered a breast cancer recurrence because it will usually have the same type of cells as the original tumor.
-



## **How common is recurrence?**

- ❖ In large research studies focusing on survivors diagnosed with in situ, stage 1 or stage 2 disease
    - ❖ 5-10% of survivors had a local recurrence at 5-year follow-up.
    - ❖ 10-15% had a local recurrence at 10-year follow-up.
-







## How common is recurrence?

- ❖ About 20% of survivors had a distant recurrence at 5-year follow-up.
  - ❖ Between 20-35 % of survivors had a distant recurrence at 10-year follow-up.
  - ❖ Regional recurrence alone is less common and can occur along with local or distant recurrence.
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## **How common is recurrence?**

- ❖ Approximately 70% of recurrences are identified within the first 5 years after diagnosis and treatment.
  - ❖ Careful follow-up care and screening during this 5-year period is essential.
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# **Does recurrence affect breast cancer survival?**

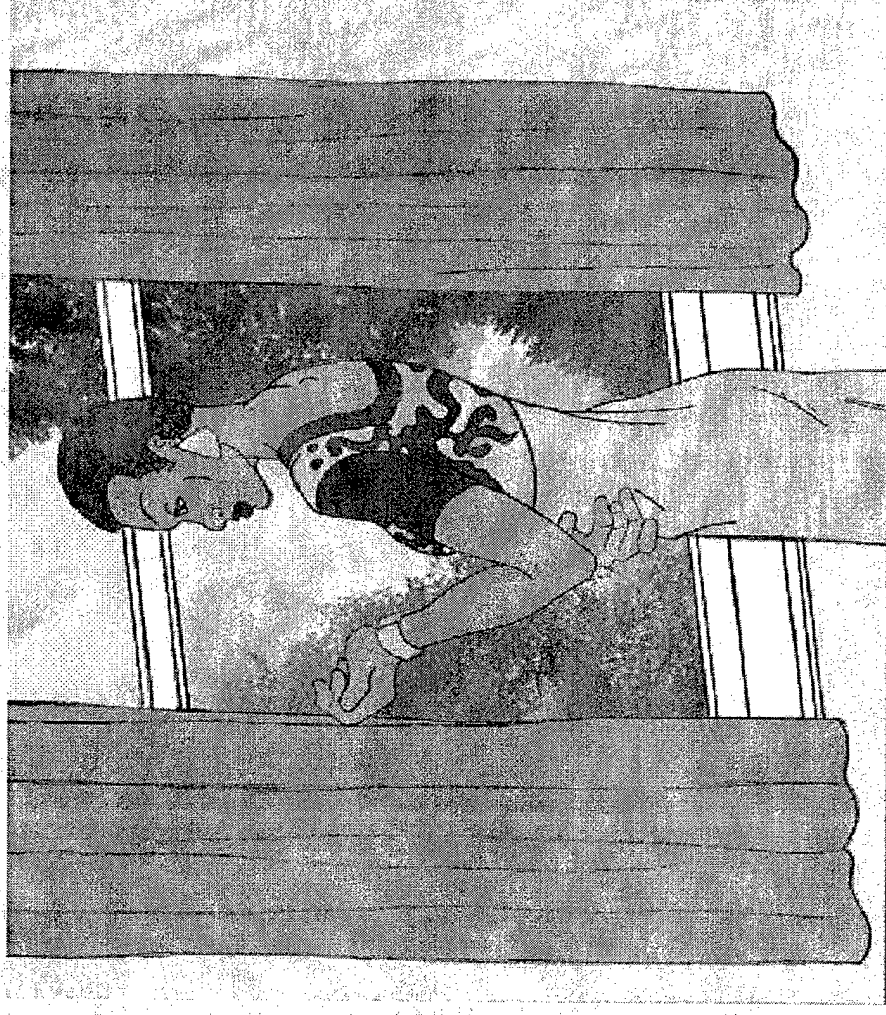
- ❖ Survival at 5-year follow-up
    - ❖ Local recurrence: 72%
    - ❖ No recurrence: 87%
  - ❖ A woman can still be a long-term survivor after a local recurrence
-

# Black survivors and recurrence

- ❖ Black breast cancer survivors may have less favorable recurrences.

- ❖ More involvement of the skin



- ❖ It is not clear whether rates of recurrence among Black survivors are higher than other groups or similar.





## **Risk factors for breast cancer recurrence**

- ❖ A survivor has little control over most of the risk factors for recurrence.
  - ❖ However, awareness of risk factors may encourage a woman to work more closely with her doctors in getting follow-up care.
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# **Risk factors for breast cancer**

## **recurrence: Age**

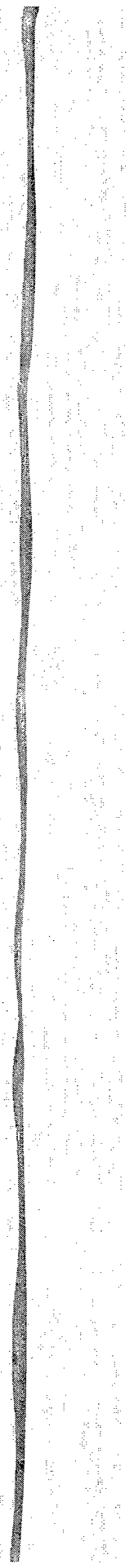
- ❖ Younger survivors are at greater risk for breast cancer recurrence
  - ❖ "Young" means anywhere from 35-50 years in most studies.
  - ❖ Younger women have a longer life expectancy and more time for cancer to recur.
-



# **Risk factors for breast cancer**

## **recurrence: Age**

- ❖ There is a relationship between menopause (change of life), hormones and cancer growth.
- ❖ Younger women may have more unfavorable cancers.







## **Risk factors for breast cancer recurrence: Features of the tumor**

- ❖ Information about one's tumor is in a pathology report that is part of one's medical records.
  - ❖ Several features are believed to be strong risk factors
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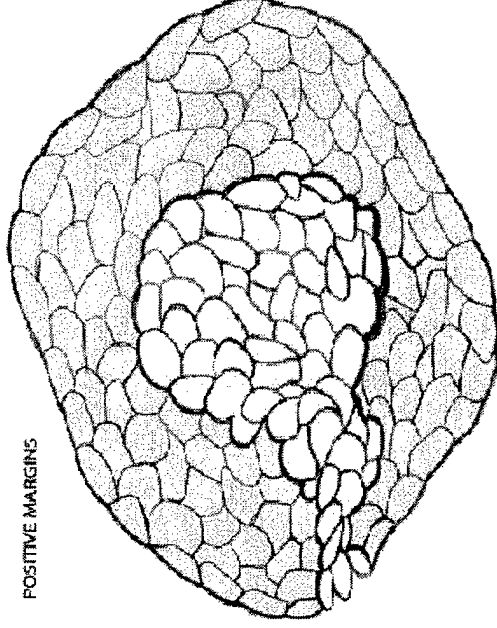
# Risk factors for breast cancer

## recurrence: Features of the tumor

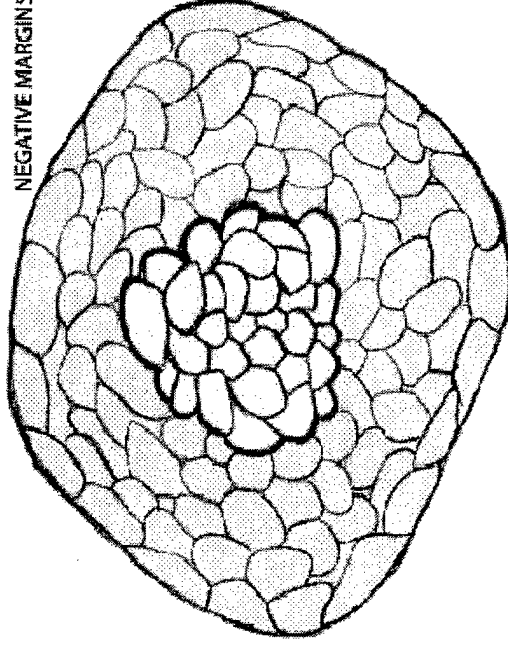
- ❖ Positive/close and unclear or unknown resection margins:

If cancer is found at the edge of tumor tissue removed during surgery (or if it is unclear or unknown if cancer is at the edge), the risk of recurrence is greater.

POSITIVE MARGINS



NEGATIVE MARGINS





## **Risk factors for breast cancer recurrence: Features of the tumor**

- ❖ Extent of intraductal cancer (cancer in breast ducts):

The more cancer found in the ducts surrounding the tumor, the higher the risk of recurrence.

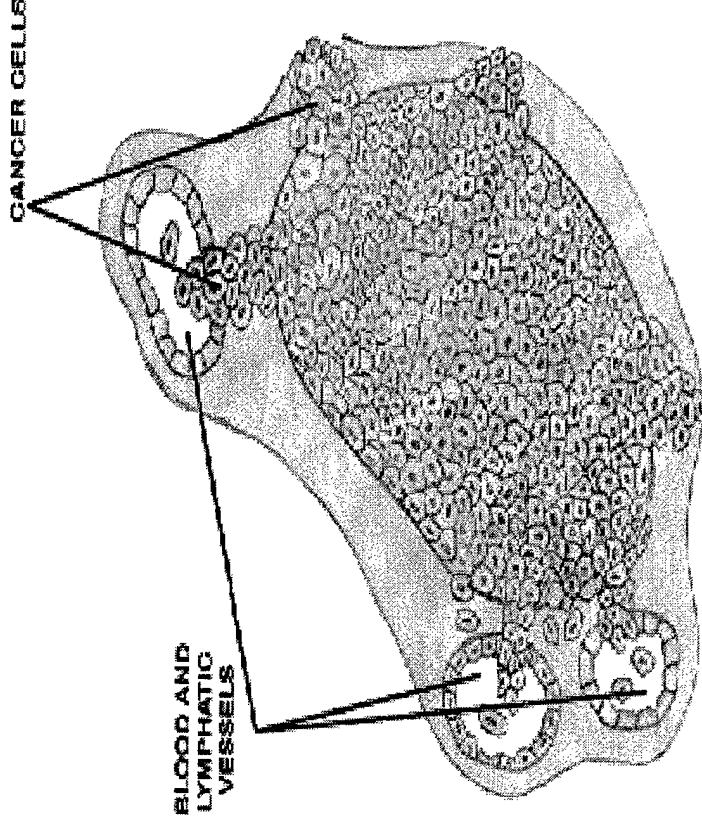
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# Risk factors for breast cancer

## recurrence: Features of the tumor

- ❖ Vascular invasion (cancer in blood/lymphatic vessels):

The more that cancer cells have entered the vessels surrounding the tumor, the greater the risk of recurrence.





## **Risk factors for breast cancer recurrence: Features of the tumor**

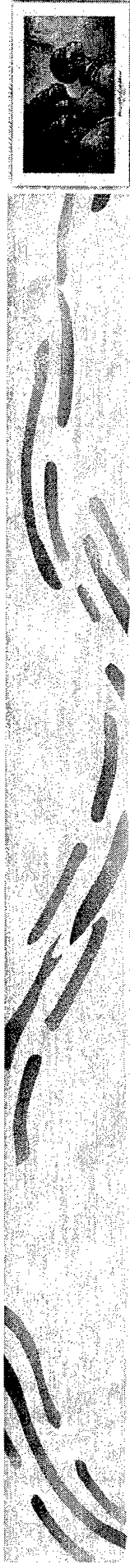
- ❖ Positive lymph nodes
- ❖ The more lymph nodes that are determined to be positive (be cancerous), the greater the chance of recurrence



## Regular follow-up care and screening for breast cancer recurrence



- ❖ Regular follow-up care and screening leads to early detection.
- ❖ There are benefits to early detection.
- ❖ Getting regular follow-up care and screening can detect a tumor at an earlier stage and when it is smaller



## **Regular follow-up care and screening for breast cancer recurrence**

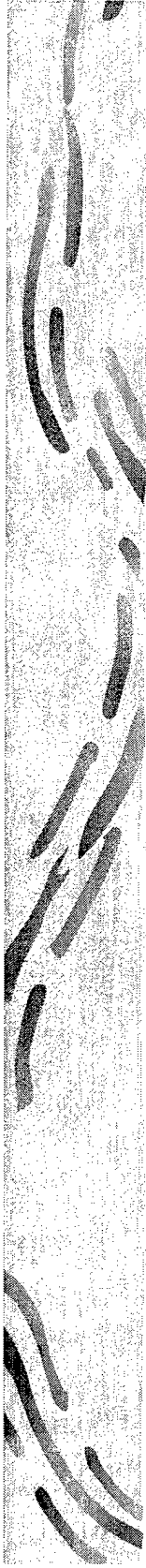
- ❖ When a survivor detects a recurrence or second primary at an early stage, she is more likely to recover.
  - ❖ Breast cancer found early is
    - ❖ more treatable
    - ❖ better controlled
-



## **Regular Follow-up Care and Screening for Breast Cancer Recurrence**

- ❖ Finding the cancer early may extend a survivor's life (survival) and improve her quality of life.
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## **Regular follow-up care and screening for breast cancer recurrence**

- ❖ Survivors who find a recurrence when the tumor is smaller and less invasive are less likely diagnosed with a distant recurrence later on in life.







# **American Society of Clinical Oncologists (ASCO) Guidelines for Follow-up Care and Screening after Breast Cancer Treatment**

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## ❖ A full physical examination and symptom history

- ❖ 2-4 times a year for the first 3 years (4-6 months)
- ❖ 1-2 times for the next 2 years (6-12 months)
- ❖ Once a year after that

## ❖ Annual mammogram (with first one performed 6 months after the end of treatment )

- ❖ Monthly breast self-exam (BSE)
- ❖ Regular pelvic exam and pap test



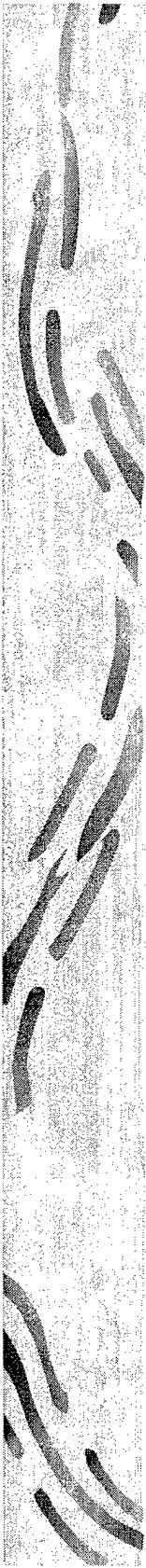
## **ASCO Guidelines: Full physical exam and symptom history**

- ❖ Approximately 70% of recurrences are detected by patients themselves based on symptoms they notice between routine visits
  - ❖ Physical exam can detect a recurrence even if the survivor has no symptoms
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## **ASCO Guidelines: Symptoms of Recurrence**

- ❖ Any changes in the breast
    - ❖ mass or skin rash
  - ❖ Symptoms of bone metastasis (most common)
    - ❖ bone pain or tenderness
  - ❖ Symptoms of pulmonary (lung) metastasis
    - ❖ Chest pain or difficulty breathing
-



## **ASCO Guidelines: Symptoms of Recurrence**

- ❖ Gynecologic symptoms
    - ❖ vaginal discharge or spotting or abdominal pain
  - ❖ Central nervous system (CNS) symptoms
    - ❖ seizures, persistent headache, changes in mental functioning, problems with movement, or sensory loss (problems seeing, hearing, etc.)
-



# **ASCO Guidelines: Symptoms of Recurrence**

- ❖ Symptoms of liver metastasis
    - ❖ Discomfort, fullness or pain in the right upper part of body, fullness or pain, weight loss
  - ❖ Other general symptoms including fatigue
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# **ASCO Guidelines: Symptoms of Recurrence**

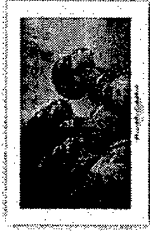
- ❖ If a survivor notices suspicious or persistent symptoms, she should talk with her doctor as soon as possible.



## **ASCO Guidelines: Annual Mammogram**

- ❖ Six months after treatment, a baseline mammogram should be performed once changes due to surgery and radiation have stabilized
  - ❖ After that, a mammogram should be conducted at least once a year
  - ❖ A doctor may order more mammograms based on findings
-





## **ASCO Guidelines: Annual Mammogram**

- ❖ Regular mammograms detect breast cancer recurrence and second primaries when tumors are smaller and at an earlier stage.



## **ASCO Guidelines: Monthly Breast Self-Exam**

- ❖ Should be performed on both breasts, even if the survivor has had a mastectomy or has a prosthesis.
  - ❖ In survivors who have had a mastectomy, local recurrence may occur in the chest wall and skin flaps.
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# **ASCO Guidelines: Regular Pelvic Exam & Pap Test**

- ❖ A vaginal/rectal examination and pap test is recommended due to the increased risk of endometrial cancer (cancer in the uterus), especially in women taking tamoxifen
  - ❖ symptoms include vaginal discharge and bleeding or spotting
  - ❖ Women who have had a hysterectomy should consult with their physician as they may be examined less frequently.
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## ASCO Guidelines

- ❖ Studies have compared these guidelines to more extensive testing, such as blood tests, bone scans, CT scans, and MRIs.
  - ❖ There is no difference between the ASCO guidelines and more extensive testing terms of
    - ❖ Time to recurrence detection
    - ❖ Mortality
    - ❖ Survival
-



## **ASCO Guidelines**

- ❖ The ASCO guidelines represent the minimum follow-up care that a survivor should receive.
  - ❖ A survivor may choose to have more extensive follow-up if she and her doctor decide that is best.
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## **Second primary breast cancer**

- ❖ If a survivor is diagnosed with cancer in the breast that was not originally affected (the opposite breast), this is referred to as
    - ❖ a second primary breast cancer
    - ❖ a new primary
    - ❖ contralateral breast cancer
-



## **Second primary breast cancer**

- ❖ This is a new cancer that is unrelated to the first and is not a recurrence.
  - ❖ 2-11% of survivors may develop a second primary.
  - ❖ Chemotherapy and tamoxifen can lower your risk of a developing a second primary
-



# **Risk factors for a second primary breast cancer**

- ❖ Younger age
  - ❖ Family history of breast cancer
    - ❖ specifically mother or sister diagnosed with breast cancer
    - ❖ Not the same as genetic risk for breast cancer
-





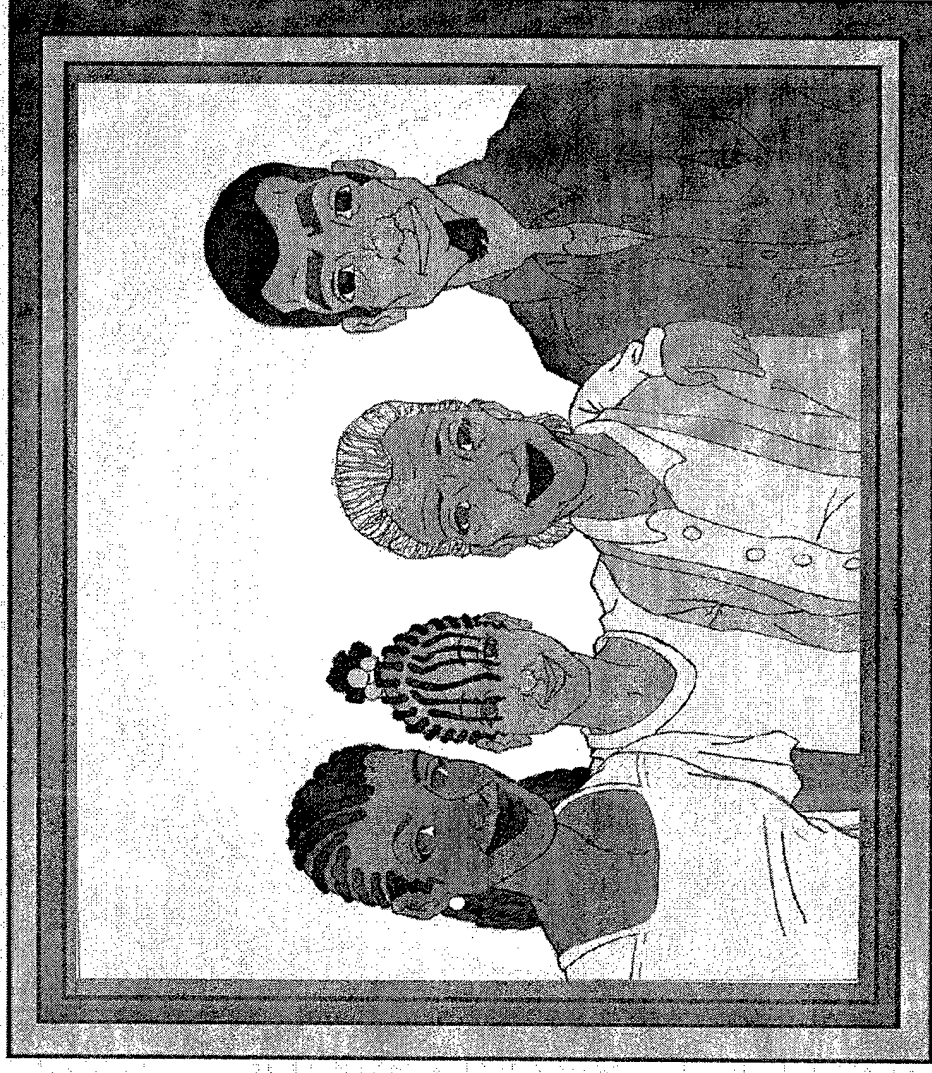
# Breast cancer genetics

- ❖ Genes are in every cell of our bodies and control different functions.
  - ❖ Genes called BRCA1 and BRCA2 control breast cell growth.
  - ❖ Mutations or changes in these genes increase the risk of breast and ovarian cancer.
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# Breast cancer genetics

❖BRCA mutations occur in about 10% of breast cancer survivors and their families.

❖Breast cancer is "passed down" through generations.





# Breast cancer genetics

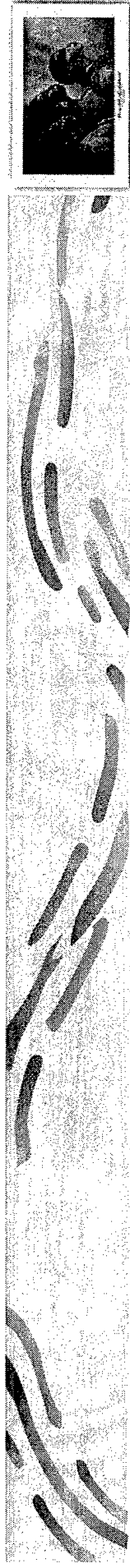
## Typically in these families:

- ❖ More than one person has been diagnosed with breast or ovarian cancer
  - ❖ Family members are diagnosed at younger ages
  - ❖ Family members may have been diagnosed with cancer in both breasts
  - ❖ There may be men in the family diagnosed with breast cancer
-



## Breast cancer genetics

- ❖ Up to 64% of breast cancer survivors who carry a BRCA mutation develop a second primary breast cancer.
  - ❖ A survivor's chance of developing a recurrence in the same breast is also increased.
  - ❖ For a survivor who has a BRCA mutation, the risk of developing ovarian cancer is up to 50%.
-





## **Genetic counseling and testing**

- ❖ Genetic testing is available to learn if you have a BRCA mutation.
  - ❖ Genetic testing involves a blood test.
  - ❖ It is important to undergo genetic counseling with a certified counselor before and after testing.
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## **Black survivors and breast cancer genetics**

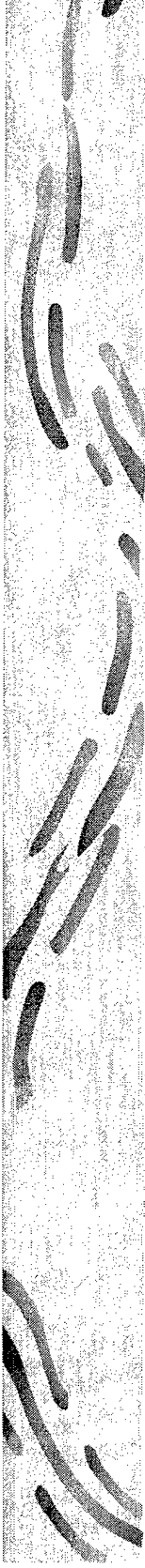
- ❖ It is unknown if BRCA mutations are more common or less common among Black people compared to other racial/ethnic groups.
  - ❖ It is known that the chance of an ambiguous or unclear result following BRCA testing is higher among Black people.
  - ❖ A mutation may be found but its effect on breast cancer is not known.
-



## **There are no formal screening guidelines for breast cancer survivors with a BRCA mutation.**


- ❖ Some organizations recommend the same follow-up care and screening as other survivors plus
    - ❖ Pelvic exam 1-2 times a year
    - ❖ Transvaginal ultrasound (with color Doppler)  
1-2 times a year
-





- ❖ Annual serum screening for CA-125, a tumor marker for ovarian cancer
  - ❖ Option of prophylactic mastectomy and prophylactic oophorectomy
    - ❖ Removing the breasts and/or ovaries for cancer prevention
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## **Follow-up care and screening among breast cancer survivors**

- ❖ Studies suggest that a surprising number of breast cancer survivors do not get adequate follow-up care after treatment, regardless of racial/ethnic background.
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## **Follow-up care and screening among breast cancer survivors**

- ❖ Survivors most likely to get a mammogram were those who were
  - ❖ treated at a comprehensive breast center
  - ❖ treated with radiation
  - ❖ employed
  - ❖ more than 6 years from diagnosis
  - ❖ originally diagnosed through a mammogram
  - ❖ lacking a recommendation from their doctor to have a mammogram



## **Black survivors and follow-up care**

- ❖ Black survivors were half as likely to have a mammogram than White survivors in one study.
  - ❖ The length of follow-up care for Black survivors was significantly shorter than that of White survivors (53 vs. 65 months) in another study.
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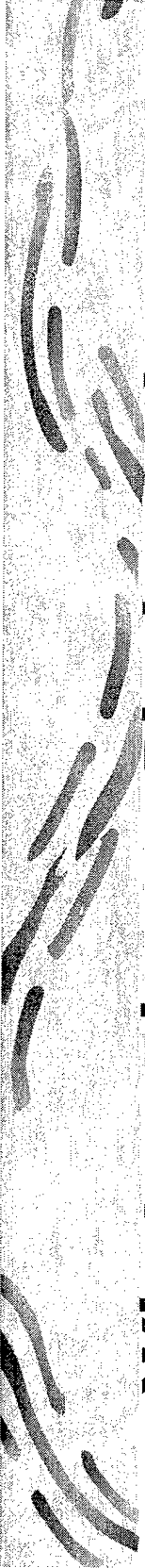
## **What keeps Black survivors from getting follow-up care?**

- ❖ Lack of knowledge about the recommended guidelines for follow-up care.
  - ❖ Not asking one's doctor the right questions about follow-up care.
  - ❖ Fear of being diagnosed with cancer again.
  - ❖ Avoiding talk or thoughts about cancer because that experience is "over."
-



## **What keeps Black survivors from getting follow-up care?**

- ❖ Lack of support from family and friends.
  - ❖ Costs of medical care.
  - ❖ Lack of awareness of programs that can help with the costs of care.
-



## **What motivates Black survivors to get follow-up care?**

- ❖ Concerns about being diagnosed again
  - ❖ Doctors' recommendations, support, care and concern
  - ❖ Support from one's family
-



## **What motivates Black survivors to get follow-up care?**

- ❖ Desire to survive to spend time with children and grandchildren
  - ❖ Relationships with other breast cancer survivors
  - ❖ Desire to live a healthy life
-



## **Take care of yourself!**

- ❖ Be active in managing your stress
    - ❖ Research does not yet shown a consistent link between stress and breast cancer.
    - ❖ However, we know that stress can affect your immune system and help cause illness.
-





## **Take care of yourself!**

- ❖ The American Cancer Society has diet and exercise guidelines for cancer prevention
    - ❖ Eat a variety of healthful foods, especially fruits and vegetables
    - ❖ Lead a physically active lifestyle
    - ❖ Maintain a healthy weight
    - ❖ Limit consumption of alcoholic beverages
    - ❖ Be aware of food safety
-



## **Teaching Breast Self-Examination (BSE)**

- ❖ Special issues for breast cancer survivors
    - ❖ Some survivors may not feel comfortable looking at their breasts or touching their breasts after cancer treatment
    - ❖ Surgery, radiation therapy and chemotherapy can change the firmness and color of the breast
-



## Teaching Breast Self-Examination (BSE)

- ❖ Special issues for breast cancer survivors
    - ❖ There may be small, hard bumps underneath or near incisions that are normal
    - ❖ If the breast has been removed, ribs will be much closer to surface of the skin
    - ❖ Breasts may often be tender
-




## Teaching Breast Self-Examination (BSE)

- ❖ During BSE, a woman is looking for any change in the breast
    - ❖ Lumps
    - ❖ Swelling
    - ❖ Dimpling
    - ❖ Changes in color of skin (redness or veins become visible)
    - ❖ Nipple discharge
    - ❖ Rashes
-



## **What is the format of a *SIS* program?**

1. Program is opened with prayer or words of devotion or inspiration.
  2. Introduce the program and the goals of the program.
  3. Show *SIS* video?
  4. Testimonies of at least 2 survivor speakers.
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5. Lay health educators discuss recurrence facts, risk factors, follow-up care guidelines, and recurrence symptoms.

6. Survivor speakers discuss reasons why survivors may or may not get care and present resources.

7. All *SIS* presenters teach and demonstrate BSE.

8. Program is closed with prayer or words of devotion or inspiration.

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